

THE UTILITY OF WEINGARTEN'S WITNESS POSITIONS IN THE
UNDERSTANDING OF COMPASSION FATIGUE IN PEOPLE WHO CARE FOR
THEIR OWN FAMILY MEMBERS WITH AIDS

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THE UTILITY OF WEINGARTEN'S WITNESS POSITIONS IN THE UNDERSTANDING OF COMPASSION FATIGUE IN PEOPLE WHO CARE FOR THEIR OWN FAMILY MEMBERS WITH AIDS

This paper explores the utility of Weingarten's (2003) witness positions in the understanding of compassion fatigue in people who care for their own family members with AIDS. The research is embedded in Weingarten's theory of witnessing and narrative theory and practice. The literature review explores the shift from hospital-based care to community/home-based care which has led to family members assuming the role of caring for their family members with AIDS, an overview of the effects of caring for AIDS patients on caregivers and an overview of Weingarten's (2003) theory of witnessing with special emphasis on the witnessing positions and their consequences. Interviews, based on narrative theory and practice in which Weingarten's theory is rooted, gave access to the participants' experiences, which were then analysed and interpreted through a framework developed from the witnessing theory. This article demonstrates the utility of Weingarten's (2003) theory of witnessing to people who are caregivers to their own family members with AIDS. I argue that witness positions occupied by caregivers during witnessing determine whether the caregivers will experience compassion fatigue. The negative consequences related to compassion fatigue that will be reviewed could probably be prevented through active, intentional, compassionate witnessing.

Key words: AIDS, compassion fatigue, home based-caregiver, narrative, witnessing

Introduction

South African communities are currently battling with HIV/AIDS. Studies on HIV/AIDS done in South Africa reflect that in the past years South African hospitals have become overcrowded and patients who have AIDS outnumber those with other illnesses. The high influx of AIDS patients has affected the quality of care. Rising health care costs have also proved problematic. Caring for people who have AIDS in the community or at home with the option of hospitalisation only when necessary, has proved to be cost effective. Other aspects influencing the shift from hospital care to home or community care include the patients' preferences to remain in the community as long as possible, a shift in the choice of where to die and the improved treatment of persons with AIDS. These factors have led to the introduction of home/community based care of patients with AIDS. With the introduction of home/community - based care of patients with AIDS, people within their home settings take care of their family members living with AIDS (Uys, 2002; Fox, Fawcett, Kelly & Ntlabati 2002; Wrubel & Folkman, 1997).

Bennet and Ross (1996) have identified the stress of caring for people with HIV/AIDS. They argue that HIV/AIDS patients require intense physical and emotional care and the terminal nature of the disease adds to the stresses of providing psychosocial as well as physical care. The aim of the study is to explore the experiences of those who care for their family members with AIDS and understand these experiences from Weingarten's theory of witnessing. By exploring the stories of family caregivers during interview sessions, the experiences and perceptions of these family caregivers will be highlighted and then interpreted within the witnessing perspective.

First, an understanding of available literature needs to be made, before an understanding of caregivers' experiences can be analysed. In reviewing literature, I have focused on the following:

- Background of the shift from hospital-based care to home-based care which has led to family caregivers taking the responsibility of caring for family members who have AIDS at home.
- The social dilemmas that people with AIDS and their caregivers face.

- The effects of caring on the caregivers.
- The framework of understanding the theory of witnessing.

The move to home-based care

According to the World Health Organisation Policy (2005), the Declaration of Alma – Ata that was signed in 1978, called for a shift in all health and development workers from specialised care to primary care in order to improve access to health care for the majority of people in the world. The Declaration of Alma – Ata describes primary care as “essential health care that is based on practical, scientifically sound, and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the community and the country can afford to maintain at every stage of their development in the spirit of self reliance and self determination” (2005, p.2). To improve the accessibility of health care referred to by the Declaration of Alma – Ata, a new type of worker is needed, a community/home-based health worker. The purpose of this role is to provide curative and preventative services to the communities and to offer a level of simplicity and quality that will target common health problems at a local level.

In AIDS care, the shift of services from hospital-based to community/home-based care and in-home care, started in North America and Europe. It was introduced because of the high cost of caring for patients, who had AIDS within the hospital. (Wrubel and Folkman, 1997). Uys, (2002) and Fox, Fawcett, Kelly and Ntlabati (2002) claim that later the shift from hospital-based care to home/ community-based care moved to Africa. In addition to the high cost of care identified by Uys (2002) and Fox et al. (2002), Burkhalter (2005) identified the health worker shortage in Africa being due to their migration to other countries. This migration is motivated primarily by factors that include low wages, few opportunities for professional development and the fear of contracting HIV and other infections because a lack of protective gear. Burkhalter (2005) also argued that in the absence of sufficient number of skilled health workers, communities rely heavily upon volunteers, family members, and community health workers in the fight against the AIDS pandemic. Burkhalter (2005) mentions that the results of a study of family and volunteer caregivers conducted in

Uganda and South Africa in 2004 indicated that the home care programmes could relieve the pressure of caring for HIV/AIDS patients on formal health and could also have social and economic benefits for patients, families and communities. The South African National Department of Health (2001) confirmed the above claims by stating that over the last decade there has been a significant increase in the overall burden of disease in South Africa. It has also been acknowledged that South Africa is facing a crisis of limited health care resources that include a shortage of hospital beds, an inadequate number of medical or nursing health professionals, lack of resources for treatment and drugs, overcrowded hospitals and the high cost of institutional care. In the midst of these problems, the ultimate option has been to introduce home-based care or community-health worker care (SA, 2001).

For the SA (2001), the concept of a Community/home-based Health Worker is driven by South African values which are: Commitment to getting closer to communities, offering better service and the need to increase health promoting activities. An integral part of this strategy are initiatives to strengthen the ability of the communities to empower themselves to participate in their own development. In the South African Department of Health context, community/home-based health workers are seen as community based generalist health workers who combine competencies in health promotion, primary health care and health resource networking and coordination. They enter communities and households and determine what health and other service requirements are needed and ensure that services are made available. They simplify life for community members by coordinating the health related activities. Their role includes providing specified primary health care and basic counselling skills, carrying out promotion activities, transferring health and wellness skills to community members and providing referrals to other sectors beyond their scope of work. They are trained in skills they are expected to use when providing their services. The Community/home-based care workers are paid a minimum wage of R1000. In rural areas, each is expected to cover 80 to 100 households while in urban areas each is expected to cover 100 to 150 households. Close cooperation between public, private and NGO sectors is pursued to ensure that the community/home-based care programmes are sustained (SA, 2001). Fox, et al. (2002) claimed that the South African Department of Health suggested five models of care, namely, community driven model, formal government sector model, integrated

home/community based care model, NGO home/community based care model, and hospice integrated community/home based care model.

This study focuses on informal family caregivers who are linked to the Hospice Integrated Community/Home based care model. According to Uys (2002), this model is an effort to link four major partners, namely, people living with AIDS and their families, community care givers and hospices and clinics and hospitals in a continuum of care. The aim of the model is to deliver quality care from diagnosis to death and bereavement. The characteristics of this model according to Fox et al. (2002) include a shift from relying on the care of professional nurses to community-based caregivers, and from institutionalised settings to home care, a focus on both the patient and the family with emphasis on decreasing the transmission of HIV by empowering families and the community with knowledge and skills. The model can be implemented in rural, semi-urban and metropolitan settings, and services are provided free or on a pro rata basis, depending on the financial situation of the patient. The community/home-based caregivers within this model are people who are recruited from the communities, trained in theory and practice of home-based HIV/AIDS care, paid a minimum wage and who work in teams under the supervision of a registered nurse. Their role includes visiting, counselling, informing, symptom control, psychological support and welfare assistance to clients. They work in close collaboration with the South African Hospice Association and clinic staff (Fox, et al. 2002).

The study conducted by Uys (2002) in South Africa explored the experiences of caregivers in Community /Home based care. The community or home based caregivers felt positive about their role, but they found it difficult to cope with the poverty and complexity of problems with which people with AIDS and their families were faced. Most families had no source of income and no food. They had no treatment either for tuberculosis or any other illness because they had no money to travel the long distances between their homes and sites where treatment was centralised. In areas that were largely rural, the distance travelled to fetch water was long. The informal caregivers within the family had difficulty of fetching water to do the laundry of the patients suffering from diarrhoea, while at the same time needing to keep an eye on the patients (Uys, 2002).

Furthermore, AIDS, like other chronic illnesses, not only has an impact on the infected individual, but also has a profound effect on the relationships within and outside the family due to the stigma associated with this illness (Miller and Murray, 1999). One of the social dilemmas that people with AIDS and their families face is that society confers shame on them by assuming that a person who has AIDS is morally defective. This assumption of moral defect, as Penn (2001) claims, is based on earlier perceptions about the source of HIV infection. HIV was first recognised among gay men in the early 1980s in the United States. Later, it became associated with drug users, bisexuality, promiscuity, adultery and infidelity, lifestyles commonly viewed as morally unacceptable. Diagnosis would be viewed as revealing a formerly kept secret of moral defectiveness. Some people who have AIDS decide to be silent about their illness as a way of protecting themselves from the pain caused by being blamed as morally defective. The illness may also cause anger to those who are suffering when they realise that nothing can take their illness away (Penn, 2001). While patients with AIDS require intense physical and emotional care that is stressful to caregivers, the terminal nature of this disease adds more stress (Bennet and Ross, 1996).

While the Community/home based care workers are helpful to the patients and their families, in the South African context they only provide care for a limited time as they are expected to attend to 80-150 households. DeCarlo and Folkman (1996) and Akintola (2004) claim that the informal family caregivers provide care for the patients at home 24 hours a day, seven days a week. The informal caregivers are unpaid people who provide most of the care in the home for the dying loved one, often lovers, spouses, friends, or family members of someone with AIDS. They are most often not professional or trained care providers. Their care-giving activities include providing practical help and nursing care for the patients at home. They also provide emotional and physical support to patients, support the patients with shopping needs, housekeeping, transportation to the clinics, as well as more basic assistance such as lifting and bathing of patients, helping patients use the bathroom, cleaning those with frequent bouts of diarrhoea among other debilitations, and feeding. When patients become seriously ill, caregivers are also likely to take on more responsibilities such as keeping track of medications, cleaning wounds and staying awake at night to attend to patients. The informal caregivers often doubt their ability to meet the

physical and psychological needs of the patients. They often worry about becoming infected. Those already HIV-positive begin to confront their own futures every time they care for a loved one with advanced AIDS. Caregiving is very demanding to the family and it may lead to physical stress as well as emotional, psychological, social and economic stress. The informal caregivers may experience numbness, headaches, backaches, compassion fatigue, or burnout from losing loved ones to AIDS, or from caring for someone who has been ill for a long time. They may also experience social stress as a result of fear of being rejected by their societies due to the stigma surrounding HIV disease. They become alienated from their friends and may experience loss of leisure time and increased isolation. Psychological stress manifests in tearfulness, sleeplessness, nightmares, and feelings of guilt, helplessness and hopelessness. The economic burden of caring for the sick sometimes falls on the caregivers who often have to deal with the increased cost of living (DeCarlo and Folkman, 1996 and Akintola, 2004).

Stubbs and Pittsburgh (2000) in their study of family caregivers claim that the family caregivers are mostly unprepared for the work they undertake and are never offered any follow-up services. They are expected to find whatever help they can by whatever means they can. They mostly act out of love, or a sense of duty, or in response to gender role expectations or the desire to honour the loved ones' wishes to stay at home instead of going to hospital. Although caregiving may bring personal satisfaction to some it may also have some implications. Caregivers who are better prepared for what might happen to their loved ones and are aware of the personal costs of caring for the dying loved ones at home are in a better position to survive and manage the caring and death of the loved one than the caregivers who are not (Stubbs and Pittsburgh, 2000).

The literature shows that the shift from hospital-based care to home-based care of AIDS patients has led to a greater responsibility for families. Some of the family caregivers take care of their family members with AIDS at home out of obligation while others do so out of compassion. Hence, caregivers can benefit from psychological; social as well as economic support to help them cope with the problems involved in caring for a terminally ill person.

The framework for understanding the witnessing positions

“By witness is meant a mode of responding to the other’s plight” (Hatley, 2000, as cited in Weingarten, 2003, p.1). Witnessing ideas are situated within narrative theory and practice. In Weingarten’s theory, witnessing is related to the witnessing of violence or violation. She describes violence as personal or structural harm done by one to another. It occurs directly between people and indirectly through structural inequalities and injustice. It has noticeable physical, psychological, spiritual or material consequences. Structural violence occurs when a social system exploits some people to the benefit of others. Violation, the focus of this research, is more subtle and difficult to notice than violence. It is compared to violence that is obviously harmful, because since it is subtle and unnoticeable in its nature, people tend to perceive it as harmless. Nevertheless, violation can be as detrimental as violence. Violation does not leave a physical mark like violence, but it can leave psychic traces. It disrupts one’s sense of meaning and makes one feel dread and fear. Violation creates victims and perpetrators (Weingarten, 2003). Weingarten (2003) regards terminal illness, which is the focus of this research, as a process that creates the experience of violation. It creates victims and witnesses. She claims that illness functions as the perpetrator and the ill or dying are victims (Weingarten, 2003). We also colloquially use phrases such as AIDS victims and AIDS the killer disease. These metaphors further construct AIDS as a perpetrator and the person who has AIDS as a victim. The caregiver of a person with the illness becomes a witness to violation.

Weingarten claims, “caring for a family member who is ill or disabled - child, spouse, parent or sibling- can cause ‘compassion fatigue’, a term coined by psychologist Charles Figley to convey the biological, psychological and social exhaustion and dysfunction that can occur when a family member has prolonged exposure to compassion stress” (2003, p. 81). Webster (1989) defines compassion as “feeling of deep sympathy and sorrow for another who is stricken by misfortune, accompanied by a strong desire to alleviate the pain or remove its cause” (p.229, cited in Figley, 2003). Thompson (2003) claims that people who care for others are vulnerable to a form of emotional exhaustion due to the compassion that this role requires. She refers to compassion fatigue as a state of emotional, physical and mental exhaustion.

One feels depleted, chronically tired, helpless, hopeless and bad, even cynical, about oneself, work, life and the state of the world (Thompson, 2003). Figley (2003) argued that compassion fatigue syndrome affects various areas of the personal functioning of the carers. These areas include cognitive, emotional, behavioural, spiritual, personal relationships, physical and work performance. Cognitively, carers experience low concentration, low self-esteem, apathy, rigidity, disorientation and thoughts of self-harm. Emotional experiences include powerlessness, guilt, anger, shutdown numbness, fear, helplessness, sadness, depression, depleted energy and increased sensitivity. Behaviourally people become impatient, withdrawn and moody, have sleep disturbances, nightmares and appetite changes and easily lose things. Spiritually, one questions the meaning of life, has a loss of purpose, decreased self-appraisal, anger towards God, a questioning of religious beliefs and loss of faith. Personal relationships are affected, as one tends to withdraw, has low interest in intimacy, mistrust, isolation from others, over protectiveness as a parent or spouse, projective anger or blame, intolerance, loneliness and increased interpersonal conflicts. Physically people experience shock, increased heart rate, impaired immune system and other somatic complaints. Work performance drops as people show low morale, low motivation, task avoidance, negativity, staff conflicts, and absenteeism, withdrawal from colleagues and poor quality and communication (Figley, 2003).

Weingarten (2003) argues that as people witness violation they assume various witnessing positions. The witness positions taken during witnessing may determine whether witnesses will experience negative consequences related to compassion fatigue or not. The positions range from a position of being an aware or unaware witness, and an empowered or disempowered witness. One can be an aware and disempowered witness, unaware and empowered witness, aware and empowered witness or unaware and disempowered witness. Awareness implies that a person has the ability to notice, anticipate, realise the meaning and effects of witnessing violation and can observe whether one is safe or not. Unawareness, on the other hand, implies lack of understanding that one is witnessing violation, its significance and effects. Empowerment refers to the possession of power, skills and knowledge aligned to one's position, status or profession. Such skills may be used to deal with the consequences of witnessing violation in order to remain safe. Disempowerment occurs when one has no control over the situation one finds oneself in, either due to

a lack of professional skills and knowledge or power position. Weingarten (2000) regards the position of being unaware and disempowered as displaying ignorance about what one is going through. The position of being an aware and disempowered witness implies realisation that one is a witness to violation, its significance and consequences, but that one lacks power, control, skills and knowledge and is thus, unable to take action towards alleviation of the harmful consequences. The position of being unaware and empowered implies that one may be unable to apply one's position of power, control, status or the skills to help oneself or others due to a lack of awareness that one is a witness to violation (Weingarten, 2002, 2003). Witness positions can change over time. Weingarten (2000) argues that it is desirable that people occupy the position of being aware and empowered witnesses. In this position, one is able to recognise that one is a witness to violation, its significance and consequences of exposure, and has control, power, knowledge and skills to thus alleviate the negative effects on oneself and on others.

Based on these witness positions, Weingarten (2003) asserts that one can be a passive, unintentional witness or an active, intentional compassionate witness. People involved in passive witnessing may either be aware or unaware witnesses. Passivity implies that witnesses experience negative effects related to compassion fatigue, but take no action towards reducing these negative effects on themselves or others. The passivity may be the result of being disempowered on how to handle the consequences of exposure to violation and unawareness of its significance and its effects. Unintentional implies that the witness had no choice on whether to be a witness to violation or not. The experience of witnessing came unexpectedly. On the other hand, Weingarten (2003) asserts that there may be active intentional compassionate witnessing which reduces the negative effects related to compassion fatigue on the witnesses and on others. Intentional witnessing implies that a person chooses to be a witness to violation and is aware of the significance of witnessing. By being compassionate, Weingarten (2003) asserts that the person makes a personal decision to open herself to the witnessing experience and thus suffers with the other with the intention of relieving that person's suffering. Figley (2002, as cited in Collins and Long 2003) asserts that caregivers cannot avoid compassion and empathy. To adjust their services to fit the responses of people who experience illness, they begin to see the world through the patients' eyes. In an effort to view the world from

suffering patients' perspective, the caregivers suffer. The meaning of compassion then is to bear the suffering of the others. Being an active witness means to alleviate the negative consequences related to compassion fatigue on him/her and those involved. Even if the acts are small, they make a difference to families, communities and the people who are witnesses (Weingarten, 2003).

Weingarten's theory of witnessing has been criticised. Her concept of compassion as a necessary aspect of the progressive use of the witnessing experiences has been seen as problematic (Pakman, 2004). Campbell (2001, as cited in Pakman, 2004) points out that compassion cannot always tell the truth. It may not always be a desirable and necessary road to good. It becomes problematic when it is made an ethical and moral priority, that is, the central concept in witnessing trauma.

The reviewed literature shows that the current context in South Africa places responsibility of caring for people with AIDS on informal caregivers. The review on compassion fatigue indicates that it may be prevalent in carers of people with AIDS. The research project aims to explore witnessing positions which may contribute to a greater understanding of how to assist caregivers in their role of witnessing their family members with AIDS.

The methodology

Data was collected from four caregivers of family members who had AIDS. The family caregivers received assistance with caring needs from community caregivers and a professional nursing sister who were under the supervision of St. Bernard's hospice, in East London. Therefore, there were two types of caregivers involved in the care of the person living with AIDS, the family member and the community caregiver employed and trained by St. Bernard's Hospice. The research focussed on the experiences of the four family caregivers who provided most of the care in the home, 24 hours a day, 7 days a week. St. Bernard's hospice has a program of training community caregivers. They are trained in home-based care, counselling and support of patients who have chronic illnesses such as cancer, hypertension, diabetes and AIDS. They work closely with a professional nursing sister in the communities around East London. Their work includes visiting the homes of patients

with chronic illnesses, bringing medication from hospice for the patients, counselling and providing baths and dressing wounds and bedsores. St. Bernard's Hospice also offers a hospitalisation option for the patients who need intravenous drips and intense medical or professional care.

I consulted the St. Bernard's Hospice Director and staff about conducting the study with the caregivers, who were caring for their family members with AIDS under their supervision. After informing them about the purpose of the study and the proposed method of collecting data, I was allowed to conduct the study. Due to the sensitive nature of this study in that HIV/AIDS is still stigmatised, there are issues of disclosure and confidentiality involved, which limited the opportunity of approaching people on my own. I requested St. Bernard's employees to arrange for me five participants who wished to participate voluntarily in the study. The participants were people who were the main caregivers of patients. They were responsible for caring for the patient and being with the patient 80-90% of the time. As the people working closely with those families, they were able to identify the main caregiver for each patient. St. Bernard's staff gave me names of five participants who agreed to voluntarily participate in the study. One of the patients died during the process of collecting data and therefore, I continued the study with four participants. The death of the patient may have affected the data if collected after the event. All participants are from the areas around East London. They consist of a mother who is a pensioner (over 60 years old) and who is caring for her son, a mother who is caring for her daughter and two women who are caring for their younger sisters.

On the first visit, the professional nurse and a community health worker responsible for the community work around East London, introduced me to the families. On later visits, a community health worker responsible for visiting the homes accompanied me. She showed me the locations and left me to do all the other work on my own. At the time of data collection, the caregivers were caring for their family members who had AIDS. I gathered the experiences from individual caregivers through interviews conducted in the caregivers' own language which was isiXhosa. Each interview was recorded for which all participants gave their permission. This enabled me to re-listen to each interview while translating it into English.

During the conversations that I had with the caregivers, I focused on the following main areas: The relationship between the caregiver and the person with AIDS, motivation to be a caregiver, experiences of being a caregiver, how the caregiver cared for herself if she needed to, and the availability of support. I asked the caregivers to narrate their experiences of witnessing their family members who had AIDS. I used the approach of story-telling motivated by narrative practice, which claims that people organize their experiences into meaningful wholes and use stories to unite the events of their lives into unfolding themes (Polkinghorne, 1988). While caregivers narrated their experiences, I paid close attention to the operations of conversation: language, metaphor, voice, and how the use of these in their conversations socially constructed their perceptions of themselves as caregivers. I asked questions as the caregivers narrated their experiences in order to clarify whatever I was not certain about and to enable them to elaborate on their experiences and to encourage them to develop their own meanings about their experiences. Freedman and Combs (1996) refers to this questioning exercise as deconstructive questioning.

Saris (1995, as cited in Aranda & Street, 2001) claims that the narrative research interview mirrors the rest of the social life with language forming the major cultural resource for participants to draw on jointly with researchers as they create meaning. For the caregivers to express themselves freely during the conversation, it was important that the language be their own language, which was isiXhosa. Anderson (1997) claims that collaborative and collective language is that which invites the other into a conversation. It includes all those involved in the process of meaning making. In this way we talk with rather than to or about people. I communicated with the caregivers in the same language, paying close attention to specific terms, phrases and metaphors used to narrate their experiences and then used these terms and metaphors in questions as a means of reflecting back their meaning.

On visiting the caregivers at their homes for an information-giving session before collecting data, I ensured that participants were fully informed about the study, its purpose and how it would be conducted. After explaining the purpose of the study verbally and also through writing to each, I invited questions and responded to them well. I read out the consent form and explained its content in their preferred



language. I informed them about the reason for recording, what would be done with the recorded conversation and also discussed the issue of anonymity to safeguard identities. For reciprocity purposes I offered the caregivers one therapy session after the interview and they all accepted it. They gave consent to participate and for the conversation to be recorded.

Backgrounds of the participants

Nothemba

Nothemba is a pensioner. She was caring for her son Thabo with AIDS. Nothemba told me that Thabo's friend informed her that Thabo was seriously ill. At the time Thabo was staying with his girlfriend in a neighbouring area. In the previous years before her son's illness she experienced the tragic loss of her youngest daughter who died away from home. She did not know where her daughter was. She told me her daughter disappointed her by falling pregnant at an early age while still at school. The incident affected their relationship adversely. Her daughter decided to run away from home and never informed her of her whereabouts and about the illness. Unknown people informed her from home about her daughter's death and she was buried away from her home. She related the pain and hardship of trying to attend her daughter's funeral. She mentioned that the incident had left a lot of pain and she vowed that she never wanted to relive the same experience of her child dying away from home.

The motivation to be a caregiver

Nothemba stated that when she heard about Thabo's illness, she went out to look for him but he refused to come home with her. She felt hurt. She said she did not want to pressure him to come home so instead she went out again to visit him. She mentioned that when she heard about Thabo's illness, she was afraid that what had happened to her daughter a few years ago might happen to Thabo. This encouraged her to look for Thabo and bring him back home alive. To her, it did not matter what illness he had because all she wanted was for him to come home so that she could take care of him. She stated, in her language,

“Emva kwalo nto ibuhlungu ndafunga ukuba asoze ibuye indehlele into yokuba umntwana wam aye kufela ezizweni, angcwatyelwe kude nekhaya, ndingamazi nokuba ubegula yintoni egcinwa ngubani” This could be translated in English as, “After that painful incident of my child dying away from home, cared for by unknown people, with an illness unknown to me and be buried away from her home, I vowed that, that would never happen to me again”.

Nothemba mentioned that she was very excited when Thabo finally came home. She claimed that from that moment she started taking care of her son.

The caregiver's experiences

Nothemba stated that when she received the news about Thabo's illness she was unhappy. She asked her daughter and her son in law to come with her when she went out to look for him. She said she was hurt when Thabo refused to come home with her. She allowed her daughter and her son-in-law to comfort her by taking her out for entertainment that afternoon. She mentioned that her soul was bitter. She cried out and poured her soul out praying to God and also appealed to her ancestors to bring Thabo back home alive. Prayer and hope sustained her during the period of waiting for her son to come home. Nothemba neither gave up on her son nor felt helpless but instead she went back again to visit him. She reported that during this visit, she had a good conversation with her son and also met his girlfriend. Without pressuring him to come home, she made him aware that he was welcome to come back home at any time.

While Nothemba was caring for Thabo, she acknowledged that the role of caring was not easy. She sometimes felt stressed out. She said that water was her life.

Whenever she felt stress, she would leave the housework and go outside to do her laundry. She claimed that water was comforting to her. Doing the laundry outside the house also gave her an opportunity to talk to people. She would later feel more relaxed. Nothemba not only gained support from her neighbours, who came to visit to see how she was doing with her son, but also the hospice staff who visited once a week to assist her in caring for Thabo. She also mentioned that together with her church members and the Mother's Union, they prayed for their children who were infected with HIV/AIDS. She claimed that on most weekends, her family members

visited and they had family braais with Thabo. Nothemba realised that AIDS was regarded as a stigma, but she claimed that she did not feel shame because everyone in her area had problems and AIDS was affecting almost everybody whether people disclosed it or not. She claimed that her son made it easy for her by disclosing the cause of his illness and they were able to talk openly about it. She told me that she accepted Thabo's illness. She said that she did all she could do as a parent when he was growing up and she could not choose for him how to live his life. She mentioned that she knew Thabo was a fun loving person who was very fond of women so when she heard about the illness she was hurt but understood. She stated that when caring for Thabo she would sense when he was feeling sad and she would leave her work and lie beside him on his bed to have a conversation with him. She said this was comforting to Thabo and her, as she usually fell asleep before Thabo did. She used the following statement in her language to summarise how she experienced caring for her son:

"Ndikonwabele kakhulu ukukhathalela umntwana wam, le nto ndiyenza ngentliziyo yam yonke." This statement can be translated as, "I am happy to be taking care of my child and I am doing this whole heartedly".

Nosipho

Nosipho is a woman who is caring for her younger sister Lucy. Nosipho is the eldest of three daughters. They lost their father several years ago. Their mother remarried and moved in with her husband and left them in the house. At the time of Lucy's illness, Nosipho stayed in her own place in a nearby settlement with her boyfriend and their daughter. Lucy and her other younger sister, who was also HIV positive stayed in their home with their children. Nosipho spent most of her time with Lucy.

The motivation to be a caregiver

Nosipho reported that when she was growing up, as an elder sister she was made to believe that she was supposed to take care of the younger ones. To her, caring for her sister, Lucy, was an obligation since her mother would not do it. It became evident that this was not her choice when she asked relatives to fetch her mother, as she felt it was her mother's duty to care for her daughter, Lucy.

The caregiver's experiences

Nosipho claimed that she was unable to sleep at night, felt worried and sad, expressed fear of what might happen to her sister, felt ill, experienced headaches, and pain at the back of her neck and body tension. She used a stimulant called snuff to reduce those feelings. She expressed anxiety that her sister was suffering from AIDS. In her language she said

"iyandikhathaza into yokuba udade wethu egula yile nto".

In the English language this statement reflects feelings of shame about the illness. She claimed it was not easy to talk to other people about AIDS because she did not know how people would react. Some sympathised with her while others laughed at them. She preferred to be silent about her problems while caring for her sister. She reported that she sometimes felt tired, but even so she had no choice but to go on. Nosipho mentioned that people from her sister's church visited but that she herself did not feel their support and that were only visiting her sister because she was a member of their church.

Pumla

Pumla is Nosipho and Lucy's mother. She took over the caring role for Lucy, her second youngest daughter, from Nosipho, her eldest daughter. When her daughter fell ill, Pumla was away and was asked to come back home by her relatives to take care of Lucy.

The motivation to be a caregiver

Pumla was asked by relatives to come back and care for her daughter Lucy. She mentioned that she believed as a mother she had an obligation to care for her daughter.

The caregiver's experiences

She related her experience of caring for her daughter as the hardest thing she had ever done in her life. She mentioned that as a mother she felt obliged to care for her

daughter and had to persevere even if it was hard. There were times she felt like running away from home, maybe to Johannesburg and never coming back. She stated that it was unbearable to see the pain her daughter was experiencing. She cried often when she saw her daughter's pain whenever she washed and changed her. She claimed that she understood why other young people commit suicide because AIDS is a bad disease. Moreover, she experienced people as unsympathetic and said they gossiped about her daughter. She preferred to be silent about her suffering and her daughter's illness, since she no longer trusted anybody. She was unable to stop putting pressure on herself. She stated that as a mother she had to persevere even if she felt too tired to go on. She reported that she had no source of support. She was always fighting with her other daughters and was afraid that they might also die of AIDS. She suffered from persistent headaches. She was managing, because she was receiving medication from her doctor to relieve her own pains and stress.

Lumka

Lumka is a woman who cares for her younger sister, Macy who has AIDS. Macy is wheel-chair bound because AIDS has affected her feet and legs. Macy's other sisters are working. Lumka also cared for her mother who died a few years ago.

The motivation to be a caregiver

Being the only one unemployed in her home, Lumka believed that she was supposed to care for Macy. She reported that being the unemployed one in her family, she also cared for her late mother.

The caregiver's experiences

Lumka claimed that she was suffering from tiredness. She was not doing anything to reduce that tiredness. She claimed that there was no time to care for herself because there were many other tasks she had to do besides the caring, such as cleaning the house, taking care of children, cooking and doing laundry. She reported she was feeling most unappreciated by her ill sister, as Macy would complain or demand

things that she was unable to provide. She would take time to prepare food for her. When she served her, Macy would not want it and demand some other food that was not readily available. Lumka's other sisters only provided the material things, but only when asked. They hardly supported Lumka in the hard work of caring for her sister or showed any emotional support. In her language she said,

"kaloku kwaXhosa kuthiwa akanconywa esaphile kuthethwa ngemisebenzi yakhe emihle xa efile"

This could be translated as "in the Xhosa culture people's good deeds are only revealed when the people who do them die". She kept silent about her plight even to other people outside the family. She believed that everybody had problems and had no time to listen to her.

Data analysis

During data analysis, I structured different reflections and events shared by the participants, into coherent stories. I then transformed their reflections into written texts. The narrative approach acknowledges the constructive nature of transcribing and translating data (Kvale, 1996).

Reading and construction of texts

I read the raw interviews repeatedly in the language of the participants in order to familiarise myself and grasp the whole content. Later, I translated the interviews from Xhosa to English. The process was not as smooth as simply translating words directly from one language to another. I discovered that some of the reflections, when translated directly to the English language, lose their meaning. For that reason, I avoided the use of a professional translator as I felt that I needed to translate the interviews myself to preserve the meaning co-constructed with the caregivers during the experience sharing. I summarized the experiences of the caregivers using pseudonyms to ensure anonymity. I condensed the interviews by discarding repetitions and reorganised the events to create a logical and temporal flow. To determine the witnessing position reflected in each story, I looked at the narrated motivation of taking care of a family member with AIDS, the narrated experiences related to compassion fatigue and the methods employed by caregivers in taking

care of themselves. The process involved isolation of related comments and language that reflected evidence of the positions of witnessing adopted by caregivers. Finally, I interpreted the data to determine the applicability of Weingarten's (2003) explanation of witnessing violation to the participants' experiences.

I looked at the following:

- To uncover intention, I looked at the comments or statements from each caregiver's narratives that reflected their motivation for caring for a family member with AIDS. These comments would reflect if witnessing was voluntary (intentional) or undertaken through obligation (unintentional).
- To uncover the position of being an aware or unaware witness, I looked at the statements or language that indicated whether the participant knew about the illness, the implications of having AIDS and if they realised that caring evokes stress and other negative results on carers.
- To uncover the empowered or disempowered position of witnessing I looked at the statements and language demonstrating skills and tools of recognising the signs and symptoms of compassion fatigue (empowered) or not (disempowered) on the part of the caregiver. Skills may be learnt or may result from one's cultural practices, beliefs, values and experiences.
- To uncover whether they were passive or active during witnessing I looked at whether the participant took actions to relieve symptoms of compassion fatigue (active) or not (passive).
- With the above evidence, I was then able to decide whether the witnessing was active intentional witnessing or passive unintentional witnessing and the reflected consequences.

The reflected experiences revealed the following findings:

(Unintentional witnessing by Nosipho, Lumka and Pumla)

Nosipho, Lumka and Pumla occupied unintentional witnessing positions. All three felt obliged to take up the role of caring for their family members who had AIDS.

Pumla felt obligated by the status of motherhood. She stated that as a mother she had to care for her daughter. Nosipho was obliged by her belief and assumption that elder siblings ought to take care of younger ones. She mentioned that being an older sister it was her duty to care for the younger ones. Lumka was obliged by an assumption that being the only unemployed sibling she had to care of her younger sister. She said that she was the only one who did not work so she had to care for her sister. In Weingarten's (2003) theory the position of unintentional witnessing involves lack of choice of whether to be a witness or not.

All four caregivers are women. From their reflected experiences it is evident that women become involved most often in unintentional witnessing of the terminally ill through the societal constructions of gender roles. Abel (1990) claims that women constitute the great majority of informal family caregivers. Stubbs and Pittsburgh (2000) argue that down the centuries, it has been taken for granted that caring is women's work. They also claim that for women, care giving is an important issue. End of life is as urgent an issue as childcare for women. The women in the family are usually members who provide the majority of assistance, even providing the nursing and personal care without significant assistance from other family members, friends or volunteers. When men find themselves needing to provide care for a family member, they are likely to hire additional female help or obtain assistance from volunteers or other family members, while women in this position are likely to do the caring themselves (Stubbs & Pittsburgh, 2000). Akintola (2004) also claims that the burden of caring for the sick weighs disproportionately on women not only because they are the main providers of care in the home but also because they have lost their male partners or have never been married. Furthermore, men rarely assist with caregiving because they are usually involved in formal or informal activities of earning an income for the family.

(Intentional witnessing position by Nothemba)

Nothemba's decision to go out and look for her son, her reflected feeling of wanting to bring him home, her willingness to care for him and acceptance of his illness, regardless of the stigma within the community, placed her in the intentional witnessing position. She stated that she wanted him to come back and feel the warmth of his home and his mother. Weingarten (2003) argues that in the

intentional witnessing position people make personal decisions to open themselves to the witnessing experience. Intentional witnessing also involves compassion whereby people decide to suffer with others while relieving their suffering.

Compassion was shown in Nothemba's case by standing together with her son in disclosing the illness. She was always sensitive to her son's feelings. She stated that there were times she would sense her son's sadness and she would decide to leave all her house-work to lie beside him on his bed. While she aimed to comfort her son, she would always sleep immediately, leaving him awake.

(Unaware and disempowered position of witnessing by Lumka, Pumla and Nosipho)

While aware that their family members were dying of AIDS, Lumka, Pumla and Nosipho never anticipated the stresses involved. Weingarten (2003) claims that aware witnesses may suffer as they agonize when they observe significant other's distress, but being aware of what they are experiencing enables them to seek ways of relieving their discomfort. Lumka, Pumla, and Nosipho's experiences reflected disempowerment as they lacked self-caring skills, identification and applying effective ways of relieving their discomfort while caring. They also lacked understanding that their position of being witnesses to their family members' illness would render them vulnerable to stress related to complaints such as headaches, tiredness, feeling unwell, relational problems as well as feelings of being unappreciated. As a result, they mostly blamed their feelings on others. The lack of necessary skills and tools enabling them to deal with their complaints more effectively led to them opting for passive ways of coping including the use of stimulants such as snuff, caffeine and medical prescriptions. Weingarten (2003) asserts that disempowerment renders one helpless as it hinders the ability to notice, anticipate and grasp the meaning and significance of the effects of witnessing on self.

Nosipho stated that she thought she could care for her sister until her death, but later the caring role became so difficult for her that she felt only a mother could withstand all the difficulties and the pains the role involved. She experienced frequent headaches and used snuff (a stimulant) to keep her going.

Pumla stated that it was her first time caring for an ill person and there were things that she was unable to handle such as when her daughter experienced epileptic seizures and when she was washing and dressing her sores, it was difficult for her to see the pain she was going through. She experienced headaches, which she relieved by taking tablets prescribed by her doctor. She worried about the conflicts she had with her other two daughters and feared that they too might also be HIV positive. She was angry with the neighbours talking behind her back about her daughter's illness. Hence she decided to remain silent about her pain.

Lumka stated while she once cared for her terminally ill mother, caring for her sister who had AIDS was different. She felt unappreciated by her ill sister. Her other siblings were not supportive to Lumka. She did not have time to care for herself as she was always busy with other house chores. She could not talk or share her feelings with other people as she felt that they had their own problems to worry about.

The understanding of the effect of Weingarten's witness positions is helpful in understanding the caregivers' responses, but there is also a need to recognise the effect the caregivers' contexts may have on the situation. These include unemployment, lack of training on caregiving, lack of facilities and resources that would make the caring role much easier and manageable, existing gender inequalities and cultural stereotypes that oblige women to take up the responsibility of caring for the ill and the effect of aged mothers caring for their daughters among affected families and communities.

(Occupation of an aware and empowered position of witnessing by Nothemba)

Weingarten (2003) points out that empowerment means that one has skills, power and knowledge that could be used to deal with the consequences of witnessing in order to remain safe. Nothemba was aware that her son was dying of AIDS. She acknowledged that while she was dedicated to caring for her son, the role of caring involved much stress. It was painful for her to see her son suffering. Nevertheless, she was able to identify her feelings of stress. She would involve herself in activities that were helpful to the relief of stress. Her experiences reflected that she was also

able to deal in a positive way with the stigma of her son having AIDS. She stated that she enjoyed caring for her son but the role of caring involved a lot of stress and pain. Whenever she felt stressed, she would take her laundry outside and wash it. Water was her life. Feeling water on her hands was healing. Being outside while doing the laundry enabled her to see people who walked down the street and who were always willing to chat with her. She would feel relieved after working with the laundry outside. She also attended the Mothers' Union weekly in her church where she prayed with other women about their problems including HIV/AIDS that infected their children. She also had a supportive daughter who visited frequently to keep them company. Her son disclosed the cause of his illness and that allowed her to also talk openly about the AIDS illness to other people. She felt that it was not appropriate to feel ashamed of the illness. She believed that AIDS affected everyone. Being open about her son's illness allowed other people to disclose their struggles about AIDS to her and also seek their advice. Nothemba and her son would also render HIV/AIDS awareness talks in their clinic to other people. She felt resourceful and helpful in her community. She also believed in the power of her ancestors. When her son could not come home, she cried in the kraal asking her ancestors to guide, protect and bring her son home.

From her reflected experiences, I suggest that Nothemba was an active, intentional compassionate witness who happened to be aware and empowered in her role as a witness. She was also aware of the significance to herself of witnessing such pain and suffering. This awareness enabled her actively manage the negative consequences of compassion fatigue at most levels fairly well. It may be suggested that this was one of the reasons why she experienced the role of being a witness to her son living with AIDS as self-fulfilling.

In addition to the positions identified by the evidence, there is also a need to recognise the context that might have an effect on the caregiver - Nothemba's history of losing her daughter, who left home because of falling pregnant as a teenager. Nothemba told me that as a mother she was disappointed and angry. Her anger affected their relationship. After giving birth to a baby, her daughter ran away from home. Nothemba mentioned that she felt guilty and hurt that her daughter may have suffered all alone of an illness never disclosed to her maybe because of fear.

She was also buried away from home. It may therefore be assumed that Nothemba was doing her best in caring for her son out of guilt at the loss of her daughter since she stated that after the death of her daughter she vowed never to experience the same pain again. Therefore this history may also be an additional factor that contributed to Nothemba accepting enthusiastically this role of witnessing with no thought of negative consequences.

Conclusion and recommendations

The research reveals that identifying the witnessing positions of the four caregivers has been useful in understanding their individual experiences. From the findings, I can tentatively suggest that the people who care for their own family members with AIDS may be witnessing violation. The positions they occupy during witnessing, determine whether they will experience positive or negative consequences related to compassion fatigue.

From Nothemba's experiences, it could be assumed that when witnessing is active, intentional and compassionate, its consequences can be less harmful. They can hardly result in compassion fatigue. From Nosipho, Lumka and Pumla's reflected experiences however, it could be suggested that when witnesses are unaware, passive and disempowered there is a possibility that they may experience negative consequences related to compassion fatigue.

While this is a useful theory, its focus on the need of shifting the witness positions for effective witnessing only, is problematic. Consideration of the social context of the illness (poverty, unemployment, lack of resources), the nature of the relationship between the caregiver and the care recipient and the personal meaning of the illness (e. g the stigma, loss of control, fore shortened future) is also vital. Besides the positions that people choose during witnessing, there are social conditions, histories, beliefs, and attitudes that would always impact on caregivers and their experiences of their role of caring that need to be looked at.

Given this, I recommend that the model be utilised for understanding the experiences of caregivers within the understanding of their contexts. Through understanding of the context, and the identification of the positions of witnessing of those who are

carers one could gain a point of entry into minimising the negative consequences of witnessing.

The usefulness of this theory is that it does not perceive the negative consequences of witnessing as mental disorders treatable through professional intervention by psychologists, social workers or psychiatrists. Weingarten's approach describes the consequences of witnessing as natural reactions to witnessing violation or the suffering of others and can be dealt with in natural ways relevant to peoples' cultures, traditions and communities. I regard the witnessing practice as being in line with the Declaration of Alma –Ata proposal of a shift from specialised care to primary care which aims at improving the access to health services for the majority of the people of the world.

With the introduction of home-based care in South Africa, this model of witnessing could also be utilised as a support program to those who care for their own family members with AIDS. The possibility of that is because witnessing aims at making people aware of themselves as witnesses to violation, the positions they take when witnessing and their consequences on them. It also provides them with tools, and skills to carry out safe and effective witnessing in the context of their family and community involvement. Safe and effective witnessing implies a strengthening awareness of what has been witnessed, performing an action that directly or indirectly enacts recognition of it, expressing emotions appropriate to it, and beginning the process of healing the self, the other, the group, or the community in relation to what has been witnessed. In this way, we could assist caregivers and their communities to feel supported to work together and witness together what AIDS is doing to them.

Limitations of the research

Within the context of this particular research involving narrative exploration, an ideal conclusion to this project would have been to consult with the caregivers and obtain their opinions, insights and ideas into research results and subsequent discussions. From a narrative perspective, this would have added value to the findings and

conclusion being a co-construction (White, 1998). However due to time constraints it was difficult to access the caregivers.

I further acknowledge that the reflected experiences and the interviews did not fully capture the participants' experiences. I also acknowledge that the findings of this study cannot be generalised because of the limited size of the study and would recommend a larger sample for further investigation.

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